UMA-B-ICI-LifeCourse in Action—February 14th, 2024

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[Recording In progress].

>> BETH WIKE: We are in webinar mode, so we have your microphone muted and a video off as well. I hope you can hear me all right at this moment. Thanks for being with us this afternoon. I am going to hand it right over to Ellen to get us started for today.

>> ELLEN KILICARSLAN: Beth had a long journey to get here today, just so everybody knows. So welcome everybody, this is our LifeCourse in action series. It is our virtual educational forum. You will hear inspiring stories and learn firsthand how to use the tools and resources that might benefit you, your family and your organization. Before I introduce our presenter for today, I just want to put a quick plug-in for next month. On March 13, we will have the session, but we're talking about positive behavioral supports on charting LifeCourse and integrating those two together. So let me get going. I want to introduce Nancy Wiley, she's a family support manager at the Berkshire County arc in Berkshire County. She is going to talk to us about mapping relationships with charting LifeCourse tools. This is one of my favorite things because it is amazing how you can see a whole family and those rules, etc. Nancy Wiley is here to present today, here she is.

>> NANCY WILLEY: Thank you, Ellen. Hello everyone and happy Valentine's Day to all of you. So, I am very happy to be here and to share with you what my experience with using this tool. Hopefully if you have any questions, I am happy to answer them as we go along. So, let's get started. Tools and action, mapping relationships. I have been using these for some time now. A wide variety of the LifeCourse tools. Ellen is correct, the mapping relationship tools are very strong ones. It can really enhance the family's knowledge, and give them piece of mind about the life ahead. Next slide, please. We are going to be sharing with you a poll, so I can see who my audience is and I will best way to address the majority of you. What is your experience with using the tools, are you joining as a parent, provider, self advocate? Maybe you hold multiple roles with their loved ones. What settings do you come from? Residential home, community living, independent living? Let us know and we will go from there. Take a moment and fill out that tool. This tool, as all of our tools, are adaptable to fit the need. When you are working with the family, you can utilize this one or many of the other ones that are available to all of us at any time. So, once we figure out and complete the tool, the poll I mean, we will move on. It's okay if you only use it part-time and that all the time. Sometimes with the tools, you don't need to use the whole thing, you might only use a section of it. I see that 22% of you use it all the time and you have heard about it but haven't used it. Sometimes, it is very difficult to get started with it. I want you to know that there is no fear involved and no wrong answers, and really no wrong way of doing it. If this is your first time learning about it, welcome. I hope you have extra knowledge on how to jumpstart without using the tools for yourself or your family. We have 24% joining us as parents. Welcome parents, I hope you find this useful. 47% is here with us as providers. Also, I hope you find this useful. 5% is self advocate, we always love to help self advocates because it is important for you to advocate on how to move forward and handle your own future. A lot of us hold dual roles, so welcome to those that 24% that are joining us today. Thank you for taking that poll. Now that I know my audience. Thank you for writing in about that and if there's anything else I can answer for you as we go along, jump in. Okay, next slide please. The tools we are going to be reviewing today our reciprocal roles and mapping relationships. We have put that together because they are very similar, yet a little different. Both can give you the outcome that you're looking for with reciprocal roles and mapping relationship rules. We will see that as we progress through this workshop today. With both of these, I want you all to know that these can be utilized at any time throughout our life span but the principal highlighted in both of these are to identify relationships in our lives and the lives of our loved ones and are being cared for and how that might change, whether that is through aging or moving on through different living situation. How might we best support the person moving on or experiencing the change. To understand how we can support them to still continue to live their best life and all the different roles that people play in all of our lives. We will compare the two. With reciprocal roles, there are two of these mapping goals. The reciprocal role tool and the mapping relationship tool. Reciprocal tool helps to identify the people that play roles in your life. The mapping one helps to identify the important people in your life and the different ways they support you in your life. So, Chantel asked, we will return to that. He will respond to that question.

>> SONJA HAECKER: She's asking and the who are we doing this for, um, is it for the recipient or - -?

>> NANCY WILLEY: That can be either or. When I did it a few years back, I can do it as a family, the whole family including the individual. They both might look different. Whatever your intention is when you put this tool into play. It could be the family, where you are doing this for. It could be there child, or the mother that they are caring for. For the individual, she was doing that for her mother, her father, her other family members and independent we were doing before. There is no way you could mess this up. It's a way to jumpstart the conversation about future plans, whatever tools you use, they are both utilized in that way. Thank you, Sonja. For mapping relationships, that one there is more about identifying who was in these roles now and if they are not in this role, who will it be? That is your looking ahead. This one here, this is the one we are focusing on for today. I want to show you how the two tools are kind of summer but a little different. You can find whichever one you want to whatever was more comfortable and usable to you. That's the way to the next slide, please.

>> SONJA HAECKER: Before we move on, Nancy, some people are asking about clarification between the different of the two tools. Can you go into depth on what separates these too?

>> NANCY WILLEY: Sure. With reciprocal tools, you want to identify the people in their lives that they share their lives, and memories but as with the mapping relationships. But the difference is with the reciprocal one is who is it giving it back to you? Who is reciprocating all of his affections? That is who you are doing this for. The next steps would be what are you going to do different and how we maintain that, maybe there people in your life that you do not recognize that are important to you. That's what reciprocal roles can open up for you. To identify more people in your life and what they can do for you and what you can do for them. Where as in mapping relationships, you start the conversation about who you love, how you make these memories and what you do with them and who supports you and how they support you. Looking ahead, if you have to ask this hard question. If it is not going to be this person that was identified, then who? What are the next steps to ensure that you can still continue to live your best life? To still make memories and still have friendships, existing ones and new ones will help you go to the bank and cash that check? Will help you do all the things you did before, but now in the future? That is a conversation we all should have with ourselves and with our families.

>> SONJA HAECKER: The next question is, what age would you suggest we use these with our students for transition support? Are these best use with a particular type of student?

>> NANCY WILLEY: So, these can be used with anyone who is able to respond with a frame of mind knowing, you do have to be careful, I will say that. I have used them with some families and it brought tears. It's hard to think about life being different than what it is today and right now. So, you have to be delicate about that. I had a family where the mother was really ill and had cancer. Who was I talking with? I was talking with the mother's sister, the daughter, the uncle. They all chimed in as to what was important and who made memories and all about. Including the individual and further down the road, the mother passed. That made it difficult, it was like full-circle. The next step is to learn how to best support the daughter who went to live with her aunt and uncle. It's important information to obtain an important information to discuss. This individual will probably mid 20s or so. It would have to be someone who can comprehend or understand or have an advocate for them who would help them to better understand the questions being asked. I hope that was helpful. Have a student be actively involved if they can't be a parents. That was a brief overview of the reciprocal roles, to identify those people that make up your life in all of these special ways. And identify the people that support you all along that we, and to explore the ways you support other people. It is not just about what we get, it's about what we give. We can identify potential for building even stronger relationships. That is a brief overview of reciprocal roles. You will find that there are some parts of that that are similar to mapping relationships. We will delve into mapping relationships to plan for the future. We will break it down for you. We have caring about and caring for. A lot of times and the people that are in the block of sharing love, exception and trust are the same people you make memories with and know about your personal interests, traditions and cultures. Sometimes it is different, but often times it is the same. So if you are talking with the family who has an elderly, they are caring for an elderly parent and wonder what to do, will give my mother the same love and affection that I give her? Who is going to help her remember all those memories that she has that they go over with all the time? In all the years of the Christmas holidays and memory many holidays and events to help support a healthy life. The looking ahead part is, if not the daughter, then who? Who will be that person? Same thing if you have a family who has a loved one who might be moving out of their home into independent living or into a residential home, who was going to do that? And what those next steps might look like for them. The next steps might look like I better have a conversation, if it's going to be my sister taking over the care of my mother, or the nursing home that will take over the care of my mother, or the residential apartment you will be now caring for my child in their home, and trying to carry on the same traditions that have meant so much throughout their whole life. That is what mapping relationships will be about. They can be very hard conversations. It is best to start early, even if they're not quite on the brink of change. It's nice to have that conversation, even if you don't do it in the order that was seen here, it can be brought up through general conversation. How did you get to your program today or to work? Did they take a bus, or did the parent bring you? Who will do that going forward it is not going to be those people? Who brought you to the bank and help to you by your vacation? Those kinds of things, all your financial needs, who is doing that now and who will be doing that, if not you? Relationships, it is so important to have a continuum of your friends and your family in your life. If there is a change in your living situation, who was going to maintain that? Who is going to make sure that your loved ones still have these meaningful relationships, whether it be with their friends or their family? Or making new friends and having community opportunities to make new friends. Who is going to advocate for that? If you have a family where the parent has done everything for them, they have advocated for them for their schooling, for their work, for whatever they want to do in life. A community event that they are interested in going, making a big decision about their life. If not them, then who? That brings a hard thought. If they don't already have one in mind, they are searching - - does that person know that? Does that person know all of the things that need to be known in order for this person to continue to live their best life? I am so glad to hear this, I am very happy that you will get this tool and start using it. So, we would like to open it up for some group discussions. Like I said, we have broken it down so one group discussion will be solely on the caring about who shares love, affection and trust. Make sure to put your answers in the chat when prompted who spends time and create meaningful memories together? I can be a lot of different people. From your job coach, your teacher, your parents, your staff, close friends. There were so many people and it is a good practice to identify, to speak it and to say it and let it be known. He knows best about your personal interest and traditions? It's important to put that out there of what is important to the individual in order for them to live their best lives. I wouldn't - - change of residency, or there has been a life-changing event in my life. Hopefully, it would open up for you things to occur that are just as wonderful. So, I am saying that there are parents, there are siblings, grandparents, cousins. All the family and close relationships you have within your family that are so important to maintain. Close friendships, as we get older, that is more important to hang on close to those. So, teachers actually end up knowing a lot about the individual. It's really good to make sure you include them in your conversations when you can. Maybe make sure they realize what is going on with your loved one. If there is anything they can do and somebody is close to them, they will do it. They will make sure you have what you need to move forward in your next phase. Coworkers, employers, roommates, all of those people are so important in our everyday living. We can't say enough about foster living and shared living. This is another extended family that is every bit as good as your own. So, to make sure that we include them in our discussions about going forward. It is not going to be these people, then what? That is the big question and that is the hard question. It is easy to list the people who you love, spend time with and who knows you best, but looking ahead, that can be a little more challenging. We usually like to give our families as much time as they need to think about that. Sometimes, they don't have an answer. Other times, they have a lot of answers. Sometimes, it's whether about what people think they know about it - - is a conversation we need to have with that person. It's important to share that information with those whom you think would be stepping in and caring for your loved ones. Folks mom and dad may have spoken to, yes. So whoever you think we will be stepping into care for your loved one, making sure they fully understand is so important. There are a lot of little tidbits that need to be shared so your loved one can continue to be cared for in the same way. Such as, maybe this person does not know how much thunderstorm affects them, or that they are afraid of heights, or they don't like scary movies. There are so many little things like that which can make a big difference. Sometimes I see here that there are neighbors, residential staff, friends, other family members. You'd be surprised how much neighbors are helpful in this area. If you have lived in the same place for a very long time, your neighbors know you pretty good. They know you walk out and get the mail every day at 2:00. It's good to stop and say hi to them every once in a while, maintain that relationship. Staff, I can't say enough about staff. Staff are the people that most of our loved ones encounter every single day. We see them when they are having a good day, we see them in their having a bad day. We help them celebrate their birthdays and other memorable times in their life. It's good to keep those communications open and to continue to include them with any changes that are going on with your loved one so they can continue to support them during this time. Whether it be a joyful time or difficult time. So, next steps. What with the next steps be? Parents take the time to figure out what the next steps might be. Offer suggestions like have a conversation. Have a conversation about what is important, what they want to? If not, then who? That can be a blow want to find out who you have been thinking this whole time suddenly says no, it is too much, I can't. Which is another reason why it is good to have these discussions ahead of time so you can properly plan for the future. So, to be developing protocol and take action when this happens and writing it down and taking pictures to share, that is an excellent idea and always good. You can build that binder of things. If your loved one happens to be nonverbal, how will that information be shared? It is good to document what is important. What has worked, what makes your loved one happy and joyful and meaningful life? Those are some of the tools you can discuss. You might come up with brand-new ones through this conversation. That is so important, to have these conversations. If you suspect a life-changing event is coming, or even if you are in the midst of one. Again, all of these can be difficult, but they can also all give you piece of mind. So yes, to advocate for the ability to move to a different location or out-of-state, what that looks like for services. So, you do have some research to do if you potentially think that could be what would happen. Then you really want to take the time and make sure that you might be able to have someone help you do that, because that can be a little daunting. Make sure you have that support team and get involved. Get involved and talk about it. Talking is the most important part of any relationship. Thank you all for this beautiful questions, and discussions. For this part of the mapping relationships. As we know, it's important to document all of the events in a person's life that brings meaning and purpose to their life. In the caring for part of this tool, we have grouped together the four boxes and the supports for day-to-day. What does that mean? That is a long conversation with family sometimes because some families offer a lot of support. Starting with, I'm getting them up in the morning. The alarm goes off and they don't get up on their own, I go do it. If they don't do it, who was going to do it? Helping them get their food prepared. Helping them get to the doctors, keeping track of when their next medical appointment should be happening. There is a lot of day-to-day needs that we take for granted. When we have these conversations, boy do they all come out. I can't say enough about having this long conversation. Also, for anyone of the people mentioned in the above category. They offer a lot of supports for day-to-day as well. For the financial part, that could be the rent payee, it could be to bring this person to the bank to cash their check, who will do that, who can be trusted to that, and who will make sure that they have what they need winter is here, do they have the right coat and red boots and stuff like that? That is important knowledge to have. Connecting to meaningful relationships and roles, that is another important thing. Without that, we don't have a lot of meaning in our lives. We need each other, people meet people. Let's make sure everyone has someone meaningful in their life. We can do that through a variety of ways like the Special Olympics what is going on right now, so many of our folks are a part of that community outings. Bring an amount of the community and showing them what is available to them in the community. Going to the library, musical events. Making sure we have those meaningful relationships and building new ones in the community. As far as advocates and supports and life decisions, how can we do that? Is through family advocates, or self advocates, through your church, through your schools, through your living situation whether it be share living or residential, or community, or in your own home with your mom and dad. Looking ahead, if it is not want to be these people that we have listed in the group discussion for who serves in this role now who would it be? Some of it may change as we move on their life and depending on what they need is for each individual. If you are in residential, the staff we change over the years. But, how will you move forward so you can ensure that the staff might change. Who else could provide the financial needs for that loved one? Often times, that is a difficult one because it has to be someone you trust. You might have to get up payee who can help look after your money and you know that you are cared for in that way. No financial exploitation. Guardianship, that is a big one. If a guardian versus another family member, an agency might take that on. Healthcare proxy is a big one, to make sure that you have someone that can act on your behalf when you cannot in the medical situation. Looking ahead for connecting to meaningful relationships, what role can tech play for a real person? Tech can play a huge role. We do have to be mindful of that. Many of our folks to use social media and often times reach out to find gratification in the relationship through those means. That is another discussion to absolutely have. Life decisions and advocating for your loved one is huge. That's another hard question, who will take on those? Enough to honor their wishes, discuss their goals in life. Yes, DVS support and having team meetings will definitely help in that area. Those are some wonderful, wonderful discussions. Thank you for all of that. Next steps, same as the top half of this mapping relationship, what to do next. How to ensure how this is a smooth transition is another discussion for sure. You will have these discussions with their family, with staff, with day programs and the DDS. We are all here to help one another and we want to see everyone thrive and live their best life. How do we do that? We get the document in some cases what is important. Who will take on certain roles. Especially for our loved ones who cannot advocate for themselves. We want to make sure that all of our valuable information moves along with them. The best way to do that is to document it, especially for the nonverbal. Even for the verbal people, is just a good way to make sure that information doesn't get missed or shared. I think when we are trying to have these conversations about how to prepare for the future, we have to be mindful of updating them as we move through life. Things change. Well might change, I trust my change, their ability to do things my change, their thoughts and their desires may change. This could be an ever-changing tool, which is perfectly fine. There is no wrong way of doing this, it is for all stages and it can be a discussion that can be reoccurring and be happy to refer back to. Often times, I would leave. I would make out one of these and give it to the family so they can reflect on. Or in addition to that, I also leave them with a blank one. Sometimes they explored with themselves, or they updated on their own. Either way, it is a discussion well worth having. Hopefully this will be able to help families prepare for the future. So, who helped us prepare for this? I think the healthcare practitioner absolutely can help you prepare for this the agency can help you prepare for this, someone you love and trust, you can work together in partnership can help you prepare for this next that part of this. I know it is a lot and it can be very overwhelming which is a hard discussion to have. It is good to do it in sections. How are you today? How did he get there, who did that? Did you choose your own clothes today? Stuff like that so you are not asking them to state all the things all at once, then moving onto the next box. You certainly can do that. So therapist and psychologist are definitely on this list to be helpful in guiding and supporting. Beautiful. Let's see, what else?

>> SONJA HAECKER: One person asked more specifically about agencies. Really, if you are DDS eligible, the first place to launch this would be meeting with the service coordinator. They can help direct you. If you are like a, I am thinking about a family model where they go from our family to somebody else's family, they can explain options like share living, what providers in your area would offer that. If you are thinking more residential, they can directly to agencies that offer that service or supported apartment or home support. You want to go to your people whether that is DDS, MRC, the school. Organize a team meeting and from that team meeting, you could be involving other providers to join in and it can ripple out. Hopefully your team grows. You might have three or four agencies, the specific agencies can vary from person to person. I'm not going to list out the agencies that could be a part of these group discussions, but there could be a lot of them were only a couple.

>> NANCY WILLEY: Thank you, Sonja. That is an excellent explanation for that. And thank you to whoever asked that question so it is shared among all of us. Are there any questions that someone has? I know it has been a lot of information in the short time that we have had together. I believe you will be receiving the slides. Thank you all for being a part of this for today. We are still here if you have any further questions. You are very welcome, you are also very welcome and thank you for supporting me throughout this time too. It's definitely a good tool.

>> ELLEN KILICARSLAN: Thank you, Nancy. I think it is a really good tool, but it is a hard tool to do. I think the advice is start early because he put everybody in the frame of mind like we have got to think about these things. It was in my life and my family's life? It can be overwhelming and intimidating because we know a lot of people are isolated and don't have a life. That is what makes it hard, I think. Thank you, this has been great, really great.

>> NANCY WILLEY: Work very well,, thank you for inviting me.

>> ELLEN KILICARSLAN: I don't know if we have any more questions. Okay. I think that's it then, thank you so much.

>> NANCY WILLEY: Thank you, so long everyone and enjoy the rest of your Valentine's Day.